Prospective Study of Factors Predicting Adherence to Medical Advice in Men With Testicular Cancer

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ABSTRACT

Purpose

To identify predictive factors of adherence to medical advice, specifically the likelihood of attendance to a recommended follow-up regimen in patients with newly diagnosed testicular cancer.

Patients and Methods

This was a prospective study measuring initially not only aspects of the doctor–patient interview, but also a range of demographic, psychological, social, and medical factors, and then recording attendance behavior on follow-up. All 209 new patients with testicular cancer referred between June 1992 and May 1995 were approached, and 184 men consented and completed questionnaires. The nonadherence end point (nonattender) was two failures to attend an outpatient appointment at least 1 month apart, despite a written reminder.

Results

Thirty-two participants (17%) were classified as nonattenders. No significant differences were found between attenders and nonattenders in the majority of psychosocial and medical variables that might have predicted nonadherence to medical advice. There was a highly significant association between nonattendance and a patient's perception of an unsatisfactory affective relationship with his clinician ($P = .005$; hazard ratio, 3.1; 95% CI, 1.4 to 6.6).

Conclusion

Patients who perceived an unsatisfactory affective relationship with their clinician that included an inability to trust the clinician and a perception that they were not being treated as “a person” were subsequently more likely to disregard medical advice regarding follow-up. Attention to the ways young men may wish to communicate with their clinicians is important, bearing in mind that they may not necessarily adhere to stereotypical images of masculine self-dependence.

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INTRODUCTION

The extent to which patients adhere to medical advice varies in a range of different illnesses, including cancer.¹⁻⁹ This may have a considerable effect on outcomes in some management protocols such that the likelihood of adherence could be a factor influencing the optimal treatment recommendation. An example of this is the policy of surveillance after orchiectomy for clinical stage I testicular germ cell cancers. The rationale is to defer treatment until those with micrometastases have demonstrated the need for chemotherapy by developing overt clinical recurrence. Overall the recurrence rate in nonseminoma is approximately 30%, and in those patients who experience recurrence, it can usually be detected while the metastases are small and relatively easy to cure.^{10,11} Surveillance is required also for patients with low-stage nonseminoma managed by

retroperitoneal lymph node dissection, although the recurrence rate is much lower at approximately 10%.¹² In metastatic nonseminoma, the cure rate and the amount of treatment needed relates to the volume of metastatic disease.^{13,14} Patients with stage I disease who do not attend follow-up assessments have a high risk of more advanced recurrence. If nonattendance was predictable, these patients could be advised of the alternative policy of immediate adjuvant chemotherapy.^{15,16} Similarly, detection of recurrence after treatment for metastatic disease may be associated with a better prognosis if the tumor burden is low.^{16a}

Nonadherence to medical advice relates to a range of possible factors, including health beliefs,^{6,17} education regarding medical management,^{18,19} underemployment,¹⁹ limited understanding of illness,¹⁹ social class,²⁰ patient dissatisfaction,²¹ anxiety,^{22,23} highly committed religious beliefs,²² and attitude to self-responsibility for health.²⁴ There

may be opportunity to respond to these if initial clinical interactions are empathetic and supportive.^{18,25} Thus it is particularly important for health care professionals to understand whether their initial interaction with a patient may influence adherence to advice, and a measure of this interaction that has not been evaluated in this context is the Medical Interview Satisfaction Scale (MISS).²⁶ We undertook a prospective study of adherence to medical advice concerning attendance to a testicular cancer follow-up clinic by assessing through self-reported questionnaires not only initial clinical interactions, but also other psychological and social factors that might predict likelihood of nonattendance. Attendance behavior was derived from hospital records.

PATIENTS AND METHODS

Setting and Participants

The study involved new patients with testicular tumor aged 18 years and older seen at the Royal Marsden Hospital, Sutton, United Kingdom, between 1992 and 1995. Attendance behavior up to 2002 was analyzed, and the median follow-up was 7 years. Men who had been informed of their diagnosis but who had not yet had their treatment regimen confirmed were approached within 8 weeks after orchiectomy and approximately 2 weeks postreferral (median time from diagnosis to enrollment was 5 weeks). Ineligibility included intellectual impairment, bilateral germ cell tumors, disease relapse, non-United Kingdom residency, and extragonadal primary disease presentation.

Design

The study design required initial completion of self-reported questionnaires to score a range of psychosocial factors followed by analysis of subsequent attendance behavior for the end point of nonadherence to medical advice. Individual consent was required to complete the questionnaires, and potential participants were approached before recommendation of a treatment plan. The patient information sheet explained that research would “help us understand the perceptions and responses of patients who have recently had a diagnosis of testicular cancer.” To avoid confounding the study, the end point of recorded outpatient attendance was not made explicit. The protocol was approved by the Royal Marsden Hospital Local Research Ethics Committee.

Patients with stage I nonseminoma managed by surveillance were assessed for attendance from the time of their first follow-up appointment. Patients undergoing chemotherapy or radiotherapy were monitored from first follow-up appointment after treatment. Follow-up constituted blood tests for tumor markers, chest radiographs, and a clinical examination. If a patient failed to attend a scheduled visit, he was sent a reminder to attend within 1 month after the failed visit. Men with two failed appointments at least 1 month apart, despite a written reminder, were classified as nonattenders. Follow-up information was obtained on all nonattenders either by direct contact or through their primary care physician. Patients who transferred care to other hospitals would be censored but not necessarily defined as a nonattender.

Statistical Methods

Attendance to medical advice was measured by follow-up attendance records. The probability of nonattendance or an event was calculated using Kaplan and Meier methods measured from the date of the first follow-up appointment. Factors were then compared by univariate and multivariate analysis using the Cox proportional hazards model. Hazard ratios (HRs) and their 95% CIs were calculated from the Cox proportional hazards model. Uncorrected *P* values less than .05 were considered statistically significant. Factor scores were dichotomized above and below the median value. The analysis was repeated in four different ways: dichotomizing at the lower quartile, dichotomizing at the upper quartile, using the actual scores as continuous variables, and dividing the data into four groups at the quartile. These were done to investigate the effect of the cutoff points on the significance of a

particular factor. A total of 206 patients were estimated to be needed to demonstrate a 20% difference in attendance at two different levels of a variable (70% to 90%) based on $\alpha = 5\%$ and power of 90%.

Questionnaires

The MISS²⁶ investigates ways in which patients perceive interaction with their attending clinician. This 26-item scale (Cronbach α coefficient = 0.93) consists of a cognitive and affective subscale (nine items each) and a behavioral subscale (eight items), with high scores denoting a positive response (Cronbach α coefficients were calculated to be 0.87, 0.86, and 0.87 respectively). Cognitive items refer to the doctor's giving explanations and information and the patient's self-perceived understanding of diagnosis, etiology, prognosis, and effects of treatment. Affective items refer to the patient's perception of the relationship he/she has with the doctor. Behavioral items measure evaluation of the physician's professional behavior, physical examination, diagnostic procedures, treatments, and dispensation of advice. Sensitivity was obtained by correlating subscale scores with indices of verbal interaction obtained by independently coded interviews between patients (including young men) and their clinicians.²⁶ For example, affective satisfaction was significantly correlated with exchanges that consisted mainly of patients telling their “story” in their own words as opposed to answering closed questions and physicians acknowledgment of patients' accounts and concerns.²⁶

The Cancer-Related Anxiety and Helplessness Scale²⁷ is a 12-item self-report measure of cancer anxiety and a “nothing more to be done” attitude. A lower score denotes greater anxiety/helplessness. The State/Trait Personality Inventory (20-item version)²⁸ measures innate and transient anxiety and consists of 10 items on each. The Course of Illness subscale of the Cancer Locus of Control Scale²⁹ is a self-administered questionnaire designed to measure the extent to which individuals perceive internal control over factors relating to the cause and course of illness. In this study, only the course of illness subscale was used. A high score is indicative of strong internal control. The Mental Adjustment to Cancer scale³⁰ shows the ways in which patients cope with their diagnosis, measuring “Fighting Spirit,” “Helplessness and Hopelessness,” “Anxious Preoccupation,” “Fatalism,” and “Avoidance.” The Health Belief Model³¹ (HBM), used in previous studies,⁶ investigates whether the behavior of patients is significantly affected by certain beliefs such as concern about health, health motivation, perceived susceptibility to the illness/relapse, perceived seriousness of the disease, and a belief that benefits outweigh costs. High scores denote the seriousness of the disease, perceived susceptibility to the disease, and relapse. Low scores denote susceptibility, including likely relapse once diagnosed. Health motivation, including intention to attend follow-up, is assessed in four items, with high scores denoting negative motivation and intention; perceived benefits are assessed in seven items, with low scores denoting the benefits of hospital visits. One of those items (“Why do you think you are asked to come to this hospital?”) included six scales ranging from 6 (“It will not help at all”) to 1 (“The cancer can be cured”). Assessment of “Barriers” (nine items) included efficacy of medical input and social disruption, with high scores denoting difficulty. Social class and other possible mediating variables were recorded, including home support and employment (Table 1).

RESULTS

A total of 209 eligible men attended the unit during the recruitment period. Twenty-five men were excluded: 13 men failed to complete questionnaires after giving consent, three men refused outright, and nine men were missed and were not asked to participate. One hundred eighty-four men consented and completed questionnaires. There were no clear demographic or medical differences between those who did or did not participate. One participant with metastases died, and seven men experienced relapse within the study period. There was no relationship between attendance and relapse. All consenting patients who completed questionnaires were monitored for attendance adherence. One attending patient transferred his care as a

Table 1. Demographic, Social, and Medical Characteristics of Patients (N = 184)

Variable	Attender		Nonattender		Cox Regression <i>P</i> *
	No.	%	No.	%	
Total patients	152	83	32	17	
Mean age, years†	35.6		31.7		.045
Socioeconomic status‡					
1, 2, 3 NM	108	59	20	11	
3, 4, 5 M	44	24	12	7	.355
Education qualification					
None	35	19	4	2	
GCSE O/A	51	28	13	7	
Degree	66	36	15	8	.630
Cancer stage					
I, II	134	73	30	16	
III, IV	16	9	2	1	.849
Histology					
Nonseminoma	69	38	16	9	
Seminoma	83	45	16	9	.633
Management					
Surgery	16	9	5	3	
Chemotherapy	58	32	12	7	
Radiotherapy	78	42	15	8	.763

Abbreviations: GCSE O/A, United Kingdom state examination (O, 16 years of age; A, 18 years of age); Degree, undergraduate and postgraduate degrees.

**P* value was calculated using Cox regression on time to nonattendance and not directly comparing the numbers on the table.

†Age was analyzed as a continuous variable.

‡Socioeconomic status is defined according to Office of National Statistics categories: 1, 2, 3 NM = nonmanual, skilled jobs; 3, 4, 5 M = manual, unskilled jobs. Retired and unemployed were categorized as "previous employment" or, when "no job," were categorized by employment of head of household.

result of social circumstances and was censored but was not considered to be a nonattender.

Table 1 shows the demographic and medical factors that characterized attenders and nonattenders. There were no differences in attendance behavior between the subgroups, including treatment received, although closer adherence to medical advice in older men was evident (HR = 0.96; 95% CI, 0.92 to 0.99; *P* = .045). After a median follow-up period of 7.7 years, 32 men were classified as nonattenders. The 5-year probability of remaining an attender was 86.3% (95% CI, 80.0% to 90.7%). A total of 62.5% of events occurred in the first 3 years of the study. By 8 years, the rate was 80% (95% CI, 72.7% to 85.6%). With 32 nonattenders, the study had 80% power to detect HRs of 2.6 or above.

Using a univariate analysis, there were no significant differences in the attendance behavior of those scoring above or below the median for the majority of psychosocial assessment (Table 2). Scores were in general unremarkable, with relatively few upper or lower extremes. Men's perceived susceptibility to testicular cancer and likelihood of relapse and/or worsening of disease, as assessed in the HBM questionnaire, showed a relatively low median score of 6 (range, 3 to 12). The difference between groups reached a *P* of .078 indicating a trend toward attenders feeling more vulnerable. Possible mediating variables, such as home support, employment, religious practice, and knowing other patients with testicular cancer, did not impact significantly on behavior.

There was a highly significant association between nonattendance and men's perception of an unsatisfactory affective relationship with their clinician as measured on the MISS²⁶ scale (Fig 1). The affective relationship remained the only significant factor when the

analysis was repeated using either a continuous scale or other cutoff points than the median score, although when the data was dichotomized at the upper quartile, none of the factors were significant. In the MISS affective scale, the HR for risk of nonattendance was not higher in the uppermost compared with the third quartile. When the scales were analyzed as continuous variables, the affective MISS scale was again the only significant factor (*P* < .02); no other factors reached a *P* value of less than .1. Men with lower scores than the median (< 38) were 3.1 times more at risk of nonattendance (95% CI, 1.4 to 6.6) than those with higher scores (*P* = .005). By 8 years, men who were scoring low overall on the Affective Scale maintained only 70% (95% CI, 57.4% to 70.3%) rate of attendance compared with those scoring high overall (≥ 38) who maintained an 89% (95% CI, 79.6% to 94.1%) rate. On multivariate analysis, only the MISS Affective Scale remained significant (*P* = .003), with an HR of 3.06 (95% CI, 1.42 to 6.63; age, *P* = .067; stage, *P* = .625; histology, *P* = .722; socioeconomic status, *P* = .401; and educational level, *P* = .625).

The items comprising the Affective Scale of the MISS were then analyzed individually, and four were significant on univariate Cox regression analysis. These were item 11 ("I really feel understood by the doctors"; *P* = .019), item 15 ("I feel the doctors accept me as a person"; *P* = .003), item 16 ("I feel the doctors haven't taken my problems seriously"; *P* = .048), and item 18 ("The doctors are people I would trust with my life"; *P* = .001). On multivariate analysis, only items 15 (*P* = .001) and 18 (*P* ≤ .001) remained significant (Table 3). Age was not included in this analysis because it was not significant in the overall multivariate analysis. Men who were unsure about whether the attending doctor was accepting them "as a person" or whether they

Attendance to Follow-Up

Table 2. Cox Regression Analysis of Psychosocial Measures

Variable	Median Score	Group*	No.	Nonattenders		P	HR	95% CI
				No.	%			
Health beliefs								
Health motivation	10	Low	97	15	15.5			
		High	87	17	19.5	.486	1.28	0.64 to 2.56
Severity	8	Low	87	19	21.8			
		High	97	13	13.4	.168	0.61	0.30 to 1.23
Susceptibility	6	Low	97	22	22.7			
		High	87	10	11.5	.078	0.51	0.24 to 1.08
Benefits	18	Low	108	16	14.8			
		High	76	16	21.1	.470	1.29	0.65 to 2.58
Barriers	16	Low	97	13	13.4			
		High	87	19	21.8	.105	1.80	0.89 to 3.64
CAHS								
Cancer anxiety	18	Low	90	18	20.0			
		High	94	14	14.9	.362	0.72	0.36 to 1.45
Cancer helplessness	23	Low	80	10	12.5			
		High	104	22	21.2	.123	1.80	0.85 to 3.81
MISS								
Cognitive	37	Low	96	18	18.8			
		High	87	14	16.1	.675	0.86	0.43 to 1.74
Affective	38	Low	88	23	26.1			
		High	95	9	9.5	.005	3.06	1.42 to 6.63
Behavior	35	Low	88	18	20.5			
		High	95	14	14.7	.298	0.69	0.34 to 1.39
State/Trait Personality Inventory								
Trait	16	Low	91	14	15.4			
		High	93	18	19.4	.537	1.25	0.62 to 2.51
State	18	Low	89	16	18.0			
		High	95	16	16.8	.832	0.93	0.46 to 1.86
CLC								
Cancer internal	16.5	Low	92	17	18.5			
		High	92	15	16.3	.651	0.85	0.42 to 1.71
Cancer external	7	Low	78	16	20.5			
		High	106	16	15.1	.347	0.72	0.36 to 1.43
MAC								
Fight	52	Low	90	15	16.7			
		High	94	18	18.1	.984	0.99	0.50 to 1.99
Helplessness	7	Low	94	18	15.7			
		High	90	14	18.9	.540	0.80	0.40 to 1.62
Anxiety preoccupation	21	Low	89	14	15.7			
		High	95	18	18.9	.468	1.30	0.64 to 2.61
Fatalism	15	Low	83	15	18.1			
		High	101	17	16.8	.791	0.91	0.45 to 1.82
Avoidance	1	Low	94	17	18.1			
		High	89	15	16.9	.633	0.84	0.42 to 1.69

Abbreviations: HR, hazard ratio; CAHS, Cancer Anxiety and Helplessness Scale; MISS, Medical Interview Satisfaction Scale; CLC, Cancer Locus of Control; MAC, Mental Adjustment to Cancer.

*Low or high dichotomized on the median score.

Fig 1. Probability of nonattendance analyzed by response on the Medical Interview Satisfaction Scale Affective Scale, grouped as either above ($n = 95$) or below ($n = 88$) the median score of 38.

would “trust their lives” to him/her were less likely to adhere to follow-up advice.

DISCUSSION

This study identified an association between attendance behavior and an affective relationship between patients with testicular cancer and their clinicians as measured by the MISS scale.²⁶ Nonattenders were ambivalent regarding the trust they had in their clinicians and were more likely to feel that they had not been accepted “as a person.” Two other items in the MISS affective scale were only significant on univariate analysis, namely, that the patient “felt understood” and that their problems had been “taken seriously.” The high association between items in this scale (Cronbach’s $\alpha = 0.86$) implies that these lost significance on multivariate analysis because of overlap and that all four factors were likely to be relevant. Analysis of the MISS scale by quartile scores suggested that it was more important to avoid a score below the median than to seek a very high score. We found no association between attendance behavior and other possible predictive variables, including social, psychological, medical, and demographic factors, although on univariate analysis, older patients were more

likely to be attenders. It may be that mature men respond to the threat of serious disease.¹⁹

Our data do not provide in-depth understanding of the perceived meaning of the terms used in the affective component of the MISS²⁶ scale. Trust in doctors is said to be built on a need for “interpersonal competence involving caring, concern, and compassion, with listening as a central focus,”³² whereas “acceptance as a person” may allude to clinicians’ respect for the patient’s idiosyncratic characteristics.³³ The high internal consistency of the affective subscale indicates reliability of the items in question.²⁶

Men who are affected by issues such as caring and compassion are exceptions to the stereotype of the stoic male patient with cancer and his need to “go it alone” when facing disease.^{33,34} This attitude may, however, play a part in how men access health provision.^{35,36} Young patients with testicular cancer are known to hide vulnerability and despise pity,³³ although some may wish to relinquish that “masculine” facade when ill.³³ We did not specifically investigate aspects of masculinity that may impact behavior. Self-report measures of masculinity are intrinsically biased.³⁷ More research using qualitative methodologies may clarify these factors in young men who are experiencing serious illness, as well as answering important questions, such as whether and why some young men find it difficult to admit to regular hospital care.

Our study differs from a Canadian study⁶ that investigated compliance to follow-up in patients with testicular cancer but had methodologic weaknesses. In that study, patients were observed retrospectively for “over a year” only. Twenty-five men were “chart reviewed” for follow-up behavior; 27 men (14 who underwent chemotherapy and 11 who underwent orchiectomy) completed questionnaires that relied on items pertaining to the HBM.³¹ Patients undergoing chemotherapy perceived their disease as “extremely dangerous” and follow-up as being more beneficial as compared with patients who had undergone surgery only. In view of the small sample size, this treatment-related difference may have been due to patient selection. Because the study was retrospective, bias may have been introduced as perceptions of disease could be affected by the outcomes of treatment. Moreover, studies using the HBM have shown differing results.³⁸ Our prospective study recognized this and addressed additional factors to HBM items that may impinge on adherence to follow-up. In addition, cultural factors may underlie the differences between the two studies, including the ways in which clinicians in the United Kingdom and United States impart information and patients receive it.³⁹

Table 3. Perceived Affective Behavior of Clinicians at Time of Diagnosis: Significant Items on Multivariate Cox Regression Analysis of the Medical Interview Satisfaction Scale

Item	Group	No.	HR	95% CI	P
15. I feel the doctors accept me as a person (y)	Strongly disagree + disagree	2	1		
	Undecided	25	0.47	0.06 to 3.92	
	Strongly agree + agree	155	0.20	0.03 to 1.51	< .001
18. The doctors are people I would trust with my life (x)	Strongly disagree + disagree	0	1		
	Undecided	15	1		
	Strongly agree + agree	168	0.35	0.14 to 0.90	< .001

NOTE. Attenders, $n = 152$; nonattenders, $n = 32$. $x = 1$ response missing, $y = 2$ responses missing (P values χ^2 test for trend). Items included in the multivariate analysis were the four that were significant on univariate analysis (see text).

There are a number of caveats with regard to interpretation of our study. Although we identified the Affective subscale of the MISS as a predictor of nonattendance, the rather small number of such events³¹ would reduce power of the study to exclude a moderate impact of other factors. We have no knowledge as to what was actually said by clinicians to their patients or whether those clinicians were junior doctors, surgeons, or medical oncologists. Nonattendance may have been caused by life events, such as bereavement or job loss, occurring within the study period. However, although this study deployed a strict definition of nonadherence to medical advice, it also gave a generous leeway to men before they were classified as nonattenders. Our results simply highlight the ways in which patients' perceptions of aspects of their affective relationship with the doctor might be associated with adherence to advice about attendance in one cancer type and in a young age group of men. We suggest that clinicians need to establish a relationship with patients that is individual and generates trust and mutual respect.

Our study has some limitations. This study was based on young adult men with testicular cancer in a single southwest London hospital where it was impossible to access robust representation of non-Caucasian groups.

In conclusion, patients who perceived an unsatisfactory affective relationship with their clinician that included an inability to trust the

clinician and a perception that they were not being treated as a person were subsequently more likely to disregard medical advice regarding follow-up. Improved communication that embraces the needs of patients with testicular cancer to establish a satisfactory doctor-patient relationship may lead to improved adherence to medical advice.

AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

The author(s) indicated no potential conflicts of interest.

AUTHOR CONTRIBUTIONS

Conception and design: Clare Moynihan, Alan Horwich

Administrative support: Louise Burchell

Provision of study materials or patients: Robert Huddart, David P. Dearnaley, Alan Horwich

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